



Joint Submission

National Disability Services and Australian Advisory Board on Autism
Developing the National Autism Strategy

# About National Disability Services

National Disability Services (NDS) is Australia’s peak body for disability service organisations, representing more than 1000 service providers. Collectively, NDS members operate several thousand services for Australians with all types of disability. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Commonwealth governments. We have a diverse and vibrant membership, comprised of small, medium and larger service providers, employing 100,000 staff to provide support to half a million of people with disability. NDS is committed to improving the disability service system to ensure it better supports people with disability, their families and carers, and contributes to building a more inclusive community.

# About Australian Advisory Board on Autism

* Australia’s first and longest-running national autism collaboration, established in 2001.
* Consists of community-driven autism associations and leading researchers from across Australia.
* Our autism associations were established by families and have long been working with and for the Autistic community, not for profit.
* Collectively, we serve and support Autistic people and their families across all life stages and in every state and territory.
* We are trusted leaders in quality, innovation and neuro-affirming practice.
* We have deep insight into what works, how it works, and why. We want to share and grow good practice in supporting Autistic people, their families and carers.
* We are proud to have established the Australian Autism Alliance in 2016 (bringing together a diverse range of autism interests).
* The AABA seeks to drive evidence-based improvements to policy, programs, practices and workforce so that Autistic people can access high quality, safe, respectful, inclusive and effective services and supports, wherever they are and whatever their circumstances

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# 1.0 Overview

National Disability Services (NDS) and Australian Advisory Board on Autism (AABA) welcomes the opportunity to provide feedback on the draft National Autism Strategy (the Strategy).

The Department of Social Services is developing a National Autism Strategy aimed at improving life outcomes for Autistic people across Australia. This Strategy will encompass all Autistic Australians, addressing key reform areas including access to services, healthcare, education, and employment. Its purpose is to guide a more coordinated, national approach to supporting Autistic people at every stage of life.

Currently, the draft Strategy is open for public feedback and will be refined based on this input. The final Strategy is expected to be presented to the government by the end of 2024. As an Australian Government initiative, the Strategy addresses areas of Commonwealth responsibility but will also consider feedback related to state and territory issues, which will be shared with respective governments.

In this submission, we will address the following questions:

* Are there any areas missing from this discussion paper that should be a priority in the Strategy?
* What does a National Autism Strategy need to achieve?

These questions will guide our analysis and recommendations, ensuring that the final Strategy is comprehensive and effective in meeting the needs of Autistic people across Australia.

**Statement on Language**

People use different words to talk about autism, and each person will have their own way of talking about autism and about themselves. Some people in the Autistic community like to use ‘Autistic person” (identity-first language), some like to say, “person with autism” (person-first language), and some are fine with using either. In alignment with work by the Australian Government, we will be using identity-first language to talk about the National Autism Strategy. This means that we will usually use the term Autistic person, Autistic people, or Autistic individual.

# 2.0 NDIS Review and the National Autism Strategy

NDS and the AABA welcome and strongly support the draft National Autism Strategy. The Strategy signals a comprehensive commitment to taking steps toward creating a more inclusive and supportive society for Autistic individuals and their families.

The Strategyhighlights the importance of raising awareness and reducing stigma. Promoting understanding and acceptance within the broader community is vital for fostering a country where Autistic individuals are valued and respected.

The Strategy is a welcome initiative that, if executed with national consistency and shared purpose, can bring about meaningful change.

NDS and the AABA look forward to seeing a well-rounded, comprehensive Strategy that addresses the diverse needs of Autistic people across their whole life span.

## NDIS Review recommendations

The NDIS Review recommendations represent a significant opportunity to strengthen the Strategy, aligning its vision and goals with practical, measurable outcomes. The proposed establishment of a Disability Outcomes Council (DOC) (Action 20.5) is particularly impactful. This council, comprising people with disability and experts, will play a pivotal role in ensuring accountability and driving continuous improvement across all levels of government and service provision. By monitoring and publicly reporting on the performance of all governments in meeting the outcomes and commitments outlined in the Disability Intergovernmental Agreement, the DOC hopes to ensure that the Strategy's vision of a safe, inclusive society is translated into tangible action.

The replacement of the current NDIS Outcomes Framework with a new Disability Support Outcomes Framework (Action 23.1) is equally significant. This new framework, developed in consultation with people with disability, carers and service providers, will provide a more comprehensive and person-centred approach to measuring outcomes. By including measurable targets and standards at the individual, provider and system levels, the new framework will ensure that the Strategy's goal of improving life outcomes for all Autistic people is actively pursued and monitored.

## Importance of reforms for the National Autism Strategy

Implementing the reforms recommended in the NDIS Review is crucial for the success and effectiveness of the Strategy. The establishment of the DOC hopes to ensure that the Strategy is implemented with national consistency and a shared purpose. This will address the current disparities in services and resources between regions, ensuring that all Autistic individuals and their families have equitable access to support and services.

Furthermore, the new Disability Support Outcomes Framework will provide a clear and measurable way to track the progress of the National Autism Strategy. By including both foundational and NDIS supports, this framework will ensure that the Strategy's objectives are comprehensive and inclusive of all Autistic individuals. It will also facilitate the sharing of best practices and resources, fostering collaboration and innovation across the country.

**Recommendation: Establish the Disability Outcomes Council (DOC)**

We recommend the swift establishment of the DOC, as outlined in Action 20.5 of the NDIS Review recommendations. This council should comprise people with disability and experts, tasked with monitoring and publicly reporting on the performance of all governments in meeting the outcomes and commitments outlined in the Disability Intergovernmental Agreement. The DOC should also oversee the implementation of the National Autism Strategy, ensuring that its vision and goals are achieved with national consistency and a shared purpose.

**Recommendation: Implement the Disability Support Outcomes Framework**

We recommend the adoption of the new Disability Support Outcomes Framework, as proposed in Action 23.1 of the NDIS Review recommendations. This framework should be developed with the input of people with disability, carers and service providers, and should include measurable targets and standards at the individual, provider and system levels. The framework should be included as a schedule in the new Disability Intergovernmental Agreement, ensuring that it is embedded in national policy and practice.

**Recommendation: Embed a culture of monitoring and evaluation**

We recommend embedding a robust culture of monitoring and program evaluation across the disability support sector and agencies administering the scheme, as suggested in Action 20.5 of the NDIS Review recommendations. This will ensure that the National Autism Strategy is continuously reviewed and improved based on the latest evidence and best practices.

# 3.0 Recommendations

## Vision, goals and guiding principles

**Recommendation: The National Autism Strategy should include the wider family unit in its goals, emphasising the importance of the entire family's wellbeing in achieving the best outcomes for Autistic individuals.**

NDS and the AABA welcome the vision, goals, and guiding principles of the draft National Autism Strategy. However, while the draft mentions a family-centred approach, we recommend that the strategy explicitly recognise the wider family unit in its goals. The wellbeing of the entire family is critical to achieving the best outcomes for Autistic individuals.

Families of Autistic individuals are crucial support networks, providing the foundational emotional, social and practical assistance needed for their well-being. Families often assist with daily activities, healthcare management and educational needs, ensuring that their Autistic loved ones can lead fulfilling lives. Families navigate complex systems, such as healthcare and social services, advocating for appropriate resources and accommodations. This advocacy is essential in overcoming the barriers that Autistic individuals often face in accessing necessary support.

Families facilitate inclusion and participation in community activities, reducing isolation. Moreover, families play a pivotal role in long-term planning, including financial security and future care arrangements. They provide stability and continuity, which is crucial for the long-term well-being of Autistic individuals.

## Outcome areas and commitments

**Recommendation: The National Autism Strategy should address the unique needs of Autistic individuals who experience autism as a disability, including those with profound autism.**

The strategy is silent on Autistic individuals who experience autism as a disability, and their families and carers.

At the most severe end of the autism spectrum, individuals experience autism as a disability, with significant challenges in communication, social interaction, sensory processing and behaviour regulation. They often require 24-hour supervision and assistance with activities of daily living.

Profound autism refers to a subset of individuals with autism who have an intellectual disability. Profoundly Autistic individuals may have significant cognitive impairments, affecting their ability to learn, understand and process information. This can make it challenging for them to acquire new skills or engage in activities independently.

Many Autistic individuals may have limited or no speech, relying on alternative forms of communication, such as assistive technology devices, to express their needs and preferences.

Sensory sensitivities are common among individuals with profound autism, leading to heightened reactions to sensory stimuli, such as sounds, lights, textures or smells. These sensitivities can cause distress and discomfort, impacting the person’s ability to engage in everyday activities and environments.

Behavioural challenges are also prevalent in profound autism, including repetitive behaviours, self-injury, aggression or difficulties with emotional regulation. These behaviours can be a means of communication or coping mechanisms for managing overwhelming sensory experiences or expressing unmet needs.

Support is vital for those individuals who experience autism as a disability; however, the strategy is silent on how this subsection of the community will access education, healthcare, community services and opportunities for social inclusion. NDS and the AABA recommends that the Strategyoutlines an approach to tailoring to the unique needs of profoundly Autistic individuals to enable their access to the resources and accommodations necessary to thrive and lead fulfilling lives. While profound disability remains in the remit of the NDIS, the failure to address this within the Strategy alienatesthose who experience autism as a disability by suggesting they do not deserve the same quality of life, inherent dignity and worth as others within the Autistic community.

**Recommendation: The National Autism Strategy should address the unique challenges faced by elderly Autistic individuals, incorporating a holistic approach that considers their specific needs and experiences.**

The strategy has limited detail on the approach for the ageing and elderly Autistic community.

Elderly Autistic individuals face a unique set of challenges as they age, stemming from the intersection of their neurodevelopmental condition and the typical aging process. Communication difficulties, sensory sensitivities, and social interactions can become more pronounced, exacerbating their challenges in navigating daily life.

One significant challenge is the increased risk of isolation and loneliness. Autistic individuals may struggle to form and maintain social connections throughout their lives and as they age. Changes in routine or living situations, or the loss of loved ones can further isolate them. This isolation can have detrimental effects on their mental health and well-being, highlighting the importance of creating inclusive communities and support networks.

Healthcare disparities also pose significant challenges for elderly Autistic individuals. They may encounter barriers to accessing appropriate medical care due to communication difficulties, sensory sensitivities, or a lack of health care providers trained in understanding and accommodating their unique needs. As a result, their physical and mental health needs may go unaddressed, leading to poorer health outcomes and reduced quality of life.

Furthermore, aging can bring about additional sensory and motor difficulties, such as declining sensory processing abilities or mobility issues, which can further impact independence and daily functioning.

It is recommended that the Strategyaddresses the challenges faced by elderly Autistic individuals. It requires a holistic approach that considers their unique needs and experiences, including access to supportive services, healthcare and social inclusion initiatives tailored to their specific requirements. Furthermore, there needs to be a commitment to supportive transition from NDIS to aged care initiatives.

**Recommendation: The strategy should elevate education from being a subset of social inclusion to a distinct priority, recognising the critical impact of quality, inclusive, and accessible education on Autistic individuals.**

**Recommendation: Implement a nationally consistent approach to support Autistic students, as recommended by the Disability Royal Commission.**

Embedding education as a subset of social inclusion diminishes the importance and impact of education and schooling on Autistic individuals. Education is a fundamental human right and should be treated as such.

Quality education in accessible and inclusive settings is a fundamental human right enshrined in the United Nations Conventions on the Rights of the Child and the Rights of Persons with Disabilities. Nonetheless many Autistic people report experiencing significant difficulties throughout their schooling, such that:

* Autistic students are suspended and expelled at a far higher rate than non-Autistic students (Cleary, M. et al 2024).
* Autistic students are four times more likely to be bullied than other students (Amaze 2019).
* Nine per cent of Autistic children need more support or assistance in school then they are receiving (Amaze 2019).

Of critical importance are supports and adjustments within mainstream schools to ensure Autistic students feel safe and supported to engage in learning. Where schools are unable to provide this, many parents of Autistic students seek out education and schooling at specialist schools. The Disability Royal Commissioners were divided on the recommendations on education segregation.

While education is primarily the responsibility of states and territories, NDS and the AABA recommends a nationally consistent approach in line with the Disability Royal Commission’s report identifying the need for better data collection, analysis and reporting to understand where additional supports are required at a school and student level. This can be done using existing mechanisms, including the Disability Standards for Education, the Nationally Consistent Collection of Data on School Students with Disability, the Australian Curriculum, and an additional monitoring of progress through IEP reporting, with data on Autistic students clearly identified.

## Implementation

**Recommendation: Ensure national consistency and shared purpose**

We recommend that the Australian Government, in consultation with the states and territories, take immediate action to ensure national consistency and a shared purpose in the implementation of the National Autism Strategy. This includes establishing clear roles, responsibilities and accountability mechanisms for all parties involved, as well as promoting collaboration and information-sharing between governments and service providers.

A unified Strategy ensures that all Autistic people, regardless of where they live, have access to the same high standards of support and inclusion. Disparities in services and resources between regions can lead to significant inequalities in access to care, education and support. Consistency is critical to prevent individuals and families from being forced to navigate varying and often confusing systems of care when between federal and state services.

Moreover, a cohesive approach allows for the effective sharing of best practices and resources, fostering collaboration and innovation. It ensures that successful programs and supports can be implemented nationally.

NDS and the AABA recommends the development and implementation of a unified, comprehensive framework that mandates regular collaboration and is applied consistently across the health, mental health, education, and justice sectors in all states and territories. This framework should ensure uniform standards of knowledge and attitudes toward autism, facilitating seamless service delivery and support for Autistic individuals.

# 4.0 Conclusion

In conclusion, both NDS and the AABA wholeheartedly support the Draft National Autism Strategy as a crucial step toward creating a more inclusive and supportive society for Autistic individuals and their families. The Strategy's emphasis on raising awareness, reducing stigma, and promoting understanding aligns with our shared goal of ensuring that all Autistic individuals can fully participate in all aspects of life, in line with international human rights.

However, it is important to note that significant investment and commitment will be required to ensure the successful implementation, measurement, evaluation, and reporting of the Strategy's outcomes. NDS and the AABA recommends ongoing engagement with Autistic individuals across the spectrum to ensure that their voices are heard, and their unique perspectives are considered in the implementation of the Strategy. Their insights and experiences are invaluable in shaping policies and programs that truly meet their needs and aspirations.

NDS and the AABA stand ready to support the implementation of the National Autism Strategy and looks forward to seeing the positive impact it will have on the lives of Autistic individuals and their families.

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# 5.0 References

Amaze, Talking About Autism: Guidelines for respectful and accurate reporting on autism and autistic people, 2019.

Cleary, M., West, S., McLean, L., Johnston-Devin, C., Kornhaber, R., & Hungerford, C. (2024). [When the Education System and Autism Collide: An Australian Qualitative Study Exploring School Exclusion and the Impact on Parent Mental Health](https://doi.org/10.1080/01612840.2024.2328251). *Issues in Mental Health Nursing*, *45*(5), 468–476.